

BMJ Open Exploring social capital for family caregivers of patients with chronic organ failure: study protocol for a concept mapping study

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ABSTRACT

Introduction Many family caregivers experience significant burdens, especially those who take care of patients with chronic organ failure. Although the social welfare system offers some material assistance, a more sustainable approach to supporting caregivers is warranted. This study aims to explore the social capital (ie, the internal strengths of a community that facilitate different social roles) available for these family caregivers.

Methods and analysis A participatory design based on Trochim's concept mapping framework will be used in this study. A total of 119 participants, including patients, family caregivers, professionals and other community members, will be recruited from the community. The study will be divided into three phases. In Phase I, qualitative methods will be used to prepare and generate statements. Participants will be asked to share their views on social capital for family caregivers through interviews. In Phase II, quantitative methods will be used to arrange these statements into a concept map, and participants will be asked to complete a questionnaire to prioritise the statements. Statistical methods will be used to create a map based on the responses. In Phase III, the concept map will be used to formulate action plans. The findings will be presented to the public to produce recommendations for social policy.

Ethics and dissemination This study was approved by The Chinese University of Hong Kong Survey and Behavioural Research Ethics Committee (Reference No.: SBRE-20-714). Informed consent will be obtained from all participants. This study will reveal which forms of social capital can be mobilised to support family caregivers of patients with chronic organ failure. Recommendations on policies to improve the caregiving experience, strengthen social capital and enhance social care will be produced. Findings will be disseminated through academic conferences and journals, as well as local media to create a greater social impact.

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INTRODUCTION

In family caregiving, family members assume the responsibilities of meeting the health and daily needs of patients at home.¹ Such carers are sometimes described as 'informal'

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study will use a participatory approach to solicit views about social capital that supports family caregivers of patients with chronic organ failure from the perspectives of different stakeholders.
- ⇒ The concept mapping framework will use statistical methods to generate visual representation of social capital available for family caregivers.
- ⇒ The consultation sessions in the final phase will ensure a balance of views and practicality of the recommendations produced based on the study findings.
- ⇒ The concept of social capital and generalisability of findings warrants consideration because this study will be conducted in Hong Kong, which is predominantly influenced by Chinese culture.

or 'family' caregivers because they engage in caregiving relationships without pay or formal training. They make significant contributions to the care of chronically ill people in many developed economies. For example, more than 43 million family caregivers in the USA provide care that is valued at US\$470 billion.² In Hong Kong, around 175 000 individuals (ie, around 2.5% of the population) are involved in family caregiving.³ These caregivers not only provide unpaid care but also fulfil the social expectations of a spouse or a child in Chinese culture.^{4,5} Given the complexity of chronic organ failure, family caregivers play a profoundly important role in the care of patients with this condition.⁶ In addition to meeting the care recipients' daily needs, these family caregivers are responsible for disease management. To alleviate the significant burden placed on them, a proactive and sustainable social care system that makes use of social capital to support caregivers in the community is needed.

Family caregiving and chronic organ failure

Family caregiving is a demanding role. Caregivers, who are often employed in other jobs,

invest additional time and resources in caring for the care recipients and the constraints of the caring role may force them to withdraw from their usual roles.⁷ This leads to several challenges, which are widely reported in the literature.^{8–10} Many carers report financial hardship due to the direct costs of home care or the need to reduce their working hours. Home care often requires specialist skills and knowledge, but support services do not meet these needs. Notably, provision of respite care is limited. These challenges result in physical and mental exhaustion and a significant burden perceived by the caregivers. Evidence suggests that this burden may be associated with poor outcomes, such as health problems (eg, depression) and impaired well-being.¹¹ In addition, a higher caregiver burden may increase the risk of hospitalisation and mortality among care recipients.¹² Proactive support is needed from the community to support these caregivers.

Some family caregivers are responsible for the care of individuals with chronic organ failure, which is an umbrella term that describes the progressive deterioration of organ function in chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD) and chronic renal failure (CRF). Despite accounting for only 0.2%–0.5% of the Hong Kong population,¹³ these patients demonstrate a remarkable need for medical care in terms of high hospitalisation and mortality rates.^{14 15} Their symptom burden is comparable to that of patients with cancer^{16 17} and has a significant impact on several aspects of life.¹⁸ In addition, these patients are characterised by a dependence on caregivers due to impaired physical capacity¹⁹ and psychosocial issues related to their life-limiting diagnoses.⁶ Such patients and their family caregivers are required to take responsibility for complex disease management, such as health monitoring, lifestyle modifications and various treatments. Unsurprisingly, caregivers have reported a significant burden that increases over time.^{6 20}

Social capital for family caregivers

Social capital describes the features of a community that can improve the efficiency of society by facilitating coordinated action,²¹ that is, a community's internal strengths. Various forms of social capital exist (figure 1), including

Social capital	
Natures	Directions
<ul style="list-style-type: none"> • Structural capital <ul style="list-style-type: none"> • Visible features • e.g., social networks, civic engagement • Cognitive capital <ul style="list-style-type: none"> • Invisible features • e.g., perception of trust, sharing 	<ul style="list-style-type: none"> • Bonding capital <ul style="list-style-type: none"> • Linking homogeneous groups • e.g., ties within family, neighbourhood, caregiver group • Bridging capital <ul style="list-style-type: none"> • Linking heterogeneous groups • e.g., ties between caregivers and professionals • Linking capital <ul style="list-style-type: none"> • Relationships between groups with different levels of power and status • e.g., interaction between caregivers and the Government

Figure 1 Schematic presentation of different types of social capital.

visible features such as participation in a social group (ie, structural capital) and invisible features such as a sense of trust (ie, cognitive capital). Social capital can also be categorised based on the direction of relationships. Interactions may link individuals or groups that are similar (ie, bonding capital), different (ie, bridging capital) or include a power difference (ie, linking capital).²² Social capital is not limited to policies and services that support caregivers but also includes different individual and social groups, as well as interactions and beliefs within a community. It has been shown to be a significant determinant of health.^{23 24} In one study,²⁵ family caregivers reported declining social capital (ie, engagement in social activities), which eventually led to stress and poverty. Another study²⁶ found that helping caregivers to strengthen social capital fostered positive experiences of caregiving. In cases of life-limiting illness, different forms of social support have been found to be associated with improvements in caregivers' burden and quality of life, mediated by caregiving self-efficacy.²⁷

Given the concept of social capital and the existing evidence, we hypothesise that identifying leaders and mobilising social support will improve the internal strengths of a community, enabling better social care (figure 2).²⁸ The first stage of achieving this change is to find out what kinds of social capital are needed. Despite the significance of social capital to family caregiving in cases of chronic organ failure, limited evidence is available because most studies have focused on the caregiver burden and general social support.^{4 29 30} Mapping social capital may identify specific dimensions that can be used to support family caregiving, thereby offering an opportunity to connect stakeholders in the community and inform the design of sustainable social policy.³¹

METHODS AND ANALYSIS

Objectives

With the overall aim of exploring the social capital available to family caregivers of individuals with chronic organ failure, the specific objectives of this proposed study are (1) to identify how social capital facilitates family caregiving by collecting statements from different stakeholders; (2) to develop a concept map to show the various forms of social capital; and (3) to make recommendations for social policy based on the identified dimensions of social capital.

Study design

This study will use a concept mapping approach to identify and display forms of social capital available for family caregivers.^{32 33} This methodology is commonly used for planning and evaluating health and social policies and programmes in a participatory manner.^{34 35} Trochim³³ proposed six steps of the concept mapping process, namely: (1) preparation, (2) generation of statements, (3) structuring of statements, (4) representation of statements, (5) interpretation of maps and (6) utilisation of

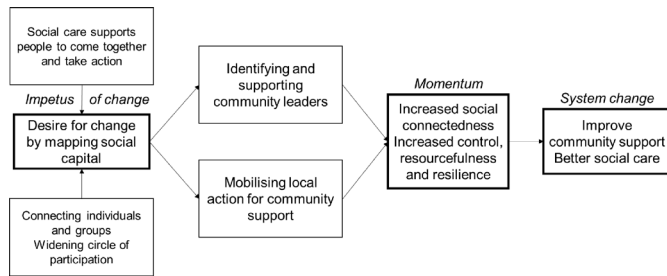


Figure 2 Programme theory of change for social care for family caregivers.

maps. By integrating qualitative and quantitative methods through this systematic process, different stakeholders’ ideas about a concept can be gathered and synthesised.

The proposed study will be conducted in three phases as shown in [table 1](#). In Phase I (preparation and generation of statements), the recruited participants will be cognitively prepared and interviewed to generate statements related to the topic. In Phase II (structuring and representation of statements and interpretation of maps), the participants will rate the statements collected. Then, concept maps will be generated using statistical methods. In Phase III (utilisation of maps), concept maps will be interpreted by the research team, participants and stakeholders to produce innovative recommendations for social policy.

Because the ongoing COVID-19 pandemic has significantly affected the study progress, Phase I participant recruitment was started in June 2021. While expecting that Phases II and III will commence in July and October 2022, respectively, all data collection procedures will be concluded by December 2022.

Participants

A purposive and snowball sampling approach will be used to ensure that different stakeholders in the community will be involved in the project. Four categories of participants will be recruited: (1) family caregivers, (2) patients, (3) professionals and (4) other community members. The patients will be adults with advanced CHF, COPD and/or CRF. Patients who live in residential care homes 1 month before the recruitment will be excluded.

Family caregivers will be adults who are spouses, children or significant others who spend at least 8 hours daily on the care of a patient with any of the abovementioned conditions.

The professionals will be qualified personnel of any discipline, including nurses, social workers, physicians and other allied health professionals, who have experience in managing patients with chronic organ failure and/or their caregivers. The other community members will be people with an interest in the field of family caregiving, such as academics and members of non-governmental organisations.

All of the participants will need to be able to communicate in Chinese and willing to provide informed consent. To involve stakeholders in the community, recruitment will take place in community settings, including clinics, health resources centres, self-help groups and other social service units. Professionals working in these settings will be invited to participate in this study. Other community members will be identified through the research team’s network, as well as via publications, news reports and social media.

Although a minimum of 20 participants has been recommended for a study of this type,³³ a mean of 72 participants has been recruited for previous concept mapping studies.³⁶ Given an average attrition rate of 39%, a total of 119 participants will be recruited, including 30 patients (10 for each condition), 30 family caregivers (10 for each condition), 30 professionals and 29 other community members.

Phase I—preparation and generation of statements

Individual semi-structured interviews will be used to collect statements about the social capital available to family caregivers. A demographic data collection form will be used to record the background information of the participants. To prepare the participants, a brief description of social capital with examples will be given to them before the interview. The interviews will be conducted by a trained research assistant using an interview guide (online supplemental material 1). This question guide was developed by the principal investigator and reviewed

Concept mapping process	Study phases	Research procedures	Research outcomes
Preparation	Phase I	<ul style="list-style-type: none"> ▶ Participant recruitment ▶ Brief description before interview 	Unsorted statements
Generation		<ul style="list-style-type: none"> ▶ Semi-structured interview ▶ Qualitative description analysis 	
Structuring	Phase II	<ul style="list-style-type: none"> ▶ Online survey 	Concept map
Representation		<ul style="list-style-type: none"> ▶ Multidimensional scaling analysis ▶ Hierarchical cluster analysis 	
Interpretation		<ul style="list-style-type: none"> ▶ Interpretation of map 	Concept map with interpretations
Utilisation	Phase III	<ul style="list-style-type: none"> ▶ Participant feedback ▶ Consultative session 	Recommendations on social policy

by five experienced researchers in nursing and social work. It includes questions about the challenges faced by family caregivers and the social capital that is available in various systems around them (ie, interpersonal relationships, community and society). Follow-up questions will be asked to clarify any unclear ideas. At the end of each interview, the interviewer will summarise the key ideas that arose. Given the safety concerns associated with the COVID-19 pandemic, the participants may opt for face-to-face, telephone or web conferencing interviews. All interviews will be audio-recorded and transcribed verbatim. The interviewer will be reminded to remain objective and non-judgemental.

Background information will be summarised using descriptive statistics. Statistical analyses will be performed using the SPSS V.25.0 software (IBM, Armonk, New York, USA). A qualitative description approach will be used to analyse the interview transcripts.^{37 38} To acquire a straightforward description of the data, two independent coders (the principal investigator and a research assistant) will read the transcripts, focusing on phrases related to family caregiving and social capital. They will code these phrases using the NVivo V.11 software package (QSR International, Melbourne, Victoria, Australia) and then generate statements by combining the codes of similar ideas. The research team will review the statements to ensure credibility and dependability.

Phase II—structuring and representation of statements and interpretation of maps

A questionnaire will be prepared based on the statements collected during Phase I. The participants will be asked to rate the importance of each statement using a 7-point numeric scale (1: 'least important' to 7: 'extremely important'). Then, they will be instructed to sort similar statements into groups. The questionnaire will be administered via an online survey system. A research assistant will send a web link via email or social media. The participants will be asked to complete the questionnaire within 2 weeks, and a reminder will be sent 2 days before the closing date. A research assistant will follow-up via telephone with any participants who fail to complete the questionnaire on time. Hard copies of the questionnaire will be sent to those who express difficulty in using the online survey system.

Multidimensional scaling (MDS) and hierarchical cluster analysis (HCA) will be used to analyse the survey data.³³ MDS is used to create a map to visualise statements as separate points, and HCA is used to identify relationships and groups among these points. The relative similarities of any two statements, as defined by the proportion of participants who sort the two statements into the same pile, will be aggregated to form a proximity matrix (of order equal to the number of statements \times number of statements). The proximity matrix will then be examined using MDS to generate initial point maps. As recommended by Trochim,³³ point maps of up to three-dimensions will be considered for ease of interpretation. A scree plot

of Kruskal's stress against dimensionality will be used to determine the optimal dimension for the final point map. Kruskal's stress values (acceptable level ≤ 0.285) and R^2 values (acceptable level ≥ 0.6) will be used to evaluate the goodness-of-fit of the model.³⁹ HCA will then be used to group the points of the final point map into clusters using Ward's algorithm. A concept map will be generated based on the importance ratings and MDS and HCA results to visualise the positions, groupings and importance of the participants' statements. All statistical analyses will be conducted using the SPSS V.25.0 (IBM, Armonk, New York, USA).

Phase III—utilisation of maps

The final phase of this study will be to formulate an action plan based on the concept map created.³³ The map and its interpretations will be shared with the participants and other members of the public to collect feedback. First, the research team will send a summary of the findings to the participants and ask for their comments. Then, three consultation sessions will be held at the study sites to discuss the findings with around 100 members of the public, regardless of their experience in caregiving. The comments collected will be used to produce recommendations on social policy to mobilise social capital to improve support for family caregivers of patients with chronic organ failure.

Rigour

The rigour of the proposed study will be evaluated according to the four criteria proposed by Lincoln *et al*,⁴⁰ namely: credibility, dependability, confirmability and transferability. To ensure credibility, the research team will triangulate the data in terms of stakeholders and member checking in Phase III. Dependability will be achieved by documenting the research process (eg, field notes) and developing audit trails. Confirmability will be enhanced by reviewing data collection and analysis within the research team. In terms of transferability, the background information of the participants and settings will be provided. A rich description of the context will be provided in the research reports.

Patient and public involvement

This concept mapping study serves as an important initial step in the co-production process that creates social capital for family caregiving.³¹ It realises the potentials of the community by connecting members and revealing internal resources. This participatory approach involves stakeholders in different phases in this study. Their voices will be synthesised using structured and collective procedures (eg, interviewing, rating). The involvement of the public is maximised by the consultation sessions. These sessions ensure a balance of views and practicality of the recommendations produced based on the study findings.

ETHICS AND DISSEMINATION

The study was approved by the Survey and Behavioural Research Ethics Committee of The Chinese University

of Hong Kong (Reference No.: SBRE-20-714). It was prospectively registered in the Chinese Clinical Trial Registry. Informed consent will be obtained from all participants. The participants' right to withdraw from the study at any point will be respected. Their confidentiality will be protected using anonymised records. Written and electronic data will be stored in a secure environment and destroyed 5 years after completion of the study. The study reports will be submitted to the government and disseminated through academic conferences and journals. To create greater impact in the community, the research team will share key findings with the public through various channels (eg, newspapers, social media, public talks). Appropriate data, such as anonymised codes and survey responses, will be stored in university's digital repository for sharing on reasonable request.

DISCUSSION

This study will be the first to explore the social capital available to family caregivers of patients with chronic organ failure. Through a participatory process, the stakeholders will contribute to the development of the concept and collectively create a concept map to display the different forms of social capital that can be found in the community. In addition, our findings will reveal the stakeholders' beliefs about what forms of support should be strengthened in the community. Based on this map, recommendations will be produced to enhance social support for these caregivers, as well as other groups that share similar situations.

It is evident that family caregivers perceive a significant burden in balancing their caregiving and normal social roles,^{7 41} and this burden may lead to poor health and well-being.¹¹ Various support services for carers, such as caregiver training, respite care and financial assistance, are commonly available in cities with established welfare systems.⁴² However, these services heavily rely on public expenditure. According to the Organisation for Economic Co-operation and Development,⁴³ member countries spend an average of 20% of their gross domestic product on social welfare. In Hong Kong, public expenditure on social welfare hit a record high of HK\$84.3 billion (approximately US\$10.9 billion) in 2019/2020.⁴⁴ As the population with long-term illnesses is expanding, the demand for caregiver support is constantly increasing. A sustainable approach to supporting family caregivers is therefore warranted. Using social capital offers one solution to this problem by exploiting the internal strengths of a community to help its own members.⁷

Studies have shown the positive effects of enhancing social capital on health outcomes of individuals.^{23 24} From an individual perspective, social capital may improve the caregiving experience. Compared with formal care that is offered by a paid caregiver, the boundaries of family caregiving are less defined.⁴⁵ Family caregivers need to devote more time and effort to care provision, and this often results in social isolation, psychological distress

and physical health problems. Social capital may provide additional interpersonal resources to connect family caregivers to the community while fulfilling their social roles (eg, through employment). Facilitating social participation is emphasised in the social policy of some developed countries. Examples include strengthening information exchange among caregivers, supporting family-friendly employment and organising promotional campaigns. Similar to these examples, social capital may increase the internal strengths of a community to improve social care for patients and their caregivers.⁴² This study will help the community to identify other forms of social capital and produce specific recommendations for how to build and mobilise social capital.³¹

This study will be conducted in Hong Kong, where the population is predominantly Chinese. Family caregiving may be influenced by traditional Chinese values about family, such as filial piety and societal responsibility.^{4 5} These characteristics may also shape a unique understanding of social capital in the Chinese context that is yet to be revealed. Therefore, consideration should be given to the generalisability of our findings. In addition, although we plan to recruit different stakeholders for the study, an ideal mix of participants cannot be guaranteed, given the purposive and snowball sampling approach.

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Contributors MSNN and WKWS conceptualised this study. WCHC, HYLC and CWHC supported the development of methodology. KCC wrote the statistical analysis plan. MSNN drafted this manuscript. WKWS, KCC, WCHC, HYLC and CWHC critically reviewed the draft. MSNN acquired the funding and will coordinate this study.

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Competing interests None declared.

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